

HOW TO START A SUPPORT GROUP

By: Renee Bernau

Starting a support group takes patience, understanding, dedication, loyalty, and determination. You are providing a service to others within the community. When I decided I wanted to start a support group, the idea just came to me. I had just left my job because I was no longer able to meet the demands of my work due to my absences, loss of memory and concentration from chronic migraines, as well as backlash from co-workers having to pick up the slack. Being the driven, creative person I am, I needed an outlet for my talents. I thought I could help others with the same ailment that has plagued me. Through my group I have found strength, developed lifelong relationships, and have learned so much more about my illness. It has opened a window of opportunity I never thought imaginable.

Getting Started

The first question you need to ask yourself is whether you are up to the challenge and commitment. I spent about a month preparing, making phone calls, and accepting reservations for my group. Begin by checking local venues, unless you will be having your group meet at your home. However, if you are starting a support group for migraine sufferers, I would advise you not to meet in your home due to the triggers of migraine sufferers. The smells of your home or family pets may be a problem for group members, plus members may be uncomfortable going to a private home. Check local churches, synagogues, community centers, libraries, village or township facilities, recreational facilities, and your place of business, to see if they have available space for this particular use. Do not choose one that charges a fee. Be mindful of a noisy location. (One example I can think of was with my group at my church. There was band practice during the winter months on our meeting nights, and the noise upset my members so much they were threatening to leave my group. So I had to switch rooms to get away from the noise so everyone could be comfortable.) Be mindful of a location that uses fluorescent lights. Although they are good for our planet, they can be painful for migraine sufferers. If you cannot stay away from these types of lights, you could bring your own lamps. Find a central location that you are comfortable with and that you yourself would go to if you joined this type of group. Establish how often you will be meeting and make sure the dates are available at the venue of your choice. For example, each of my groups meets once a month. I reserved each venue for two hours, but you may only need an hour.

Getting the Word Out

Getting the word out about your group is key. Give your group a name that describes what you do. The name will help advertise your message. Ask the venues you are looking into if they have monthly newsletters, a website, pamphlets, or calendars to advertise your group. Spread the word by making a brochure or flyer, and post it at local stores, libraries, any place that has a community bulletin board, and put them in mailboxes in your neighborhood. Ask if you can post a flyer in your place of business and your doctors' offices. If you are internet savvy, consider building a website and have the venue where your meetings are held link to your site. Around the time when my group first started, the church where my meetings take place held a support/share group fair on a Sunday before and after services highlighting all the groups available through the church. We had a booth and printed brochures to hand out to the congregation. Two group members assisted me in answering questions and signing people up for the group. See if your venue can offer you some additional exposure like this.

I have learned so many people would like support for migraine. Everyone knows someone who suffers from migraine. Word of mouth is the best advertisement, so tell people in your family, friends, co-workers, and health care providers. Use your address book. When I decided to start my support group, I called my local newspaper and asked if my group could be added to their bi-weekly calendar featuring support groups in the area. They appreciated the uniqueness of a migraine support group so much they decided to do a feature on my life with migraine and what led me to start a support group for migraine. This article alone brought in over half my group members.

The First Meeting

Once you have named your group, found the venue, decided how often you will meet, and how to get the word out, you are ready to meet. At your first meeting, have as much information as you can give about your group printed to distribute to new members. Create a comfortable environment for everyone. (I must warn you that some people who come to your first meeting may never come back. It is just not for everyone.) Have a sign-in sheet with spaces for member's name, phone number, and email address. I gave my group a packet that had an information sheet that asked if they wanted their phone number and email added to a group roster to be shared with other group members. gave members a questionnaire on what they wanted to get out of the group, and how often they are plagued by migraines. The questionnaire is important so you can address individual needs in a group setting later and can possibly pay special attention to a specific problem one-on-one with a member. It is important to show your members you can be trusted, they can feel comfortable with you, and you're there to help them. Make sure to stress that anything said in your group setting is strictly confidential. I give all members a

confidentiality agreement to be signed and returned to me. Your first meeting will probably last longer than the rest. My regular meetings are scheduled for two hours but we rarely use the allotted time. The length of the meeting will depend on your members' needs. If you have access to email, I suggest you set up a separate email address for group members only. Members should be able to reach you for support.

Keeping the Group Going

You need to find a way to keep people interested. I bring books I have read regarding migraine, DVD's to watch on migraine and the nervous system, and articles in magazines and newspapers that are relevant. Consider bringing in a guest speaker. For example, ask a doctor you or one of your members sees on a regular basis for migraine to come and answer questions and speak about migraine and new treatments. My family and friends are always contributing ideas and material too. When I can, I make copies for everyone so they can read the material at home or share it with family and other migraine sufferers. You could subscribe to the National Headache Foundation's newsletter as a group. Their website is www.headaches.org. 'Neurology Now' is a magazine that is often in doctors' offices. Their website is www.neurologynow.com. They give free subscriptions to sufferers and to doctors' offices. I find that my members enjoy reading what's new in migraine. Consider making a list of all the migraine websites you know and distributing it to your members. Members can bring new information they have gathered as well. You could take on a special project or join forces with a charity or foundation, if members agree. We have joined with the Migraine Research Foundation, and my group made a pact to try to help others who suffer as we do. Their website is www.migraineresearchfoundation.org. I encourage you to do the same within your group and community.

As time goes on, find a second in command, either a volunteer or ask someone you see who has the potential to be a group leader. Since we are all migraine sufferers, there may be times when you will need a backup. The group shouldn't suffer because you cannot be there due to illness or vacation. Your second in command should have the same drive and goals as you do for the group. He or she can run the group when you are away.

Dealing With Potential Problems

There may be times when you need to interrupt someone who is disruptive to your group. Everyone should have a chance to share. You don't want someone monopolizing the conversation, but if he is struggling more at that meeting than usual, he may need more time to talk. I have lost members due to a disruptive person who was frequently interrupting other members and talking about subjects unrelated to what the group was discussing. I should have shown my leadership skills better and stopped a potential problem before

it became a real problem. Sometimes people join a support group because they just need someone to talk to and a sense of belonging. You can investigate local groups that better fit their specific needs and suggest them to that person.

My group has drawn “healers” and people who want to share success stories as well. I have had three different people join my group whose goal was to recruit or sell migraine supplements, drugs, powders, etc. They were helped or cured by these treatments and tried to use our group as a place for furthering their success. Although this was great for them, our group was upset by their sales tactics. This lowered group morale and created false hope. I know now to simply ask for their information and what they are selling and tell them that I will pass on the information to my members. You may have to tell them not to come to meetings again unless asked. You might use them in the future as a guest speaker if your group agrees it would be beneficial.

In Closing

All in all, your options are endless. Use your imagination to keep things interesting for your group. Encourage your members to give their own ideas and use them too. Providing understanding and support is the greatest gift you can give others. For more information, contact the Migraine Research Foundation at info@migraineresearchfoundation.org or 212-249-5402. Alternatively, you can email me at notjustaheadache@yahoo.com. Together we can make a difference.